

*probably Nov. 26 1967*

JUL 25 1968

LAW-MEDICAL COLLOQUIUM - SUNDAY A.M.

BAM: Opens

DH: One concern is about class discrimination in the application of the sort of ground rules we were talking about yesterday. For example, I can imagine an affluent hospital serving affluent clientele. Let's say, just to make a start, that a ritzy hospital in Birmingham, Alabama, administered by a Mr. Connor, who formerly was sheriff of that county and since has gone into hospital administration, and these admirable guidelines come in to [018] being . . . so now patients who come to them primarily are executives of the U.S. Steel firm in Birmingham and so on, and the question is where will they get organs for these executives and the obvious source is the Negro community. Is there a real problem here about the application of even the very fair and reasonable standards that we have tried to set up?

BAM: Your argument might be cutting the other way. I think your point is still valid in either direction. It may very well be that the least likely place where one could get an organ would be in the Negro community at least if the donee knew about it.

DH: That's right. Well, that was the problem actually with blood transfusions during the War. There were units in the American Army that would not take blood known to come from Negroes.

JL: Yes, that's right but this is obviously a fairly general problem I suspect to be worldwide. . . .

RG: Well, to some degree this problem I'm sure already exists not in this kind of a context but in Seattle and . . . Josh, you were up there, you know about this, they have a great many more people who need to get on the kidney machine than they can accomodate. Therefore

they have to make judgments about who's going to get on it. Certainly until we get to the point where there is no lack of organs and I suppose that's going to be quite a way off, this problem is going to be faced all the time. One can see it faced in our own hospital where transplantation is going forward, where you've got a community in which inevitably you might get a certain number of people from your own university community who need this, and then some people from the outside. How are you going to handle this problem and in what sort of a way?

JL: Well you solve it the same way you do in employment. If you maintain a registry of the ethnic origin of the organs and the ethnic status of the people who are going to receive them and you would be obliged to submit statistics showing that there's an equitable distribution of organs by race.

RG: You're not going to take into account any other factor at a time when you don't have enough to go around?

JL: Well, I don't see that it's any different from any other kind of discrimination. [047] If it's been outlawed, you then wonder how far you're going to push your techniques of proving that discrimination has not occurred. You can push it into absurdity. But the absurdity I just mentioned seems to be no different than the questionnaire we had to fill out for jobs. Is there a difference?

BAM: This is going to get more complicated to the very extent, for example, using your term ethnic in some way or another you list the Jews, but the Jews violently resist having organ transplants. You're going to wind up with another kind of a twist in which there are going to be substantial sub-groups who are going to be asking to be discriminated against in this regard.

DH: [054] Well you know what's happened with blood. Most of the blood comes from so-called professional donors. About 60% of blood comes from people who are paid on some regular basis to give blood. I think the main difference between medical centers is how careful they are about screening these people as an available source.

JL: Well, I think that does introduce the question as to the extent to which the state should enjoin a market in organs; that is, to what extent should it be possible for there to be financial or similar considerations in the availability or exchange of organs. Now some of that would be hidden in the surgeon's fee and a good surgeon will be one who knows how to get organs readily [063] but he's not paid for the organs, he's paid for the transplantation. But I think there would be questions of enforceability of contracts involving the sale of blood and that sort of thing.

DH: Has anyone ever tried? I'm talking about needing 7,000 kidneys and trying to buy them, particularly as kidneys are paired.

JL: Well there's one example. An Egyptian according to the story had in fact hired a number of people because he knew he was going to require a transplant in the next few years. He paid not one but several people for a lifetime promise that if and when the time came anyone of them would be available depending on the surgeon's evaluation of them as prospective donors. And it is very easy to see all kinds of subtleties in the ways in which there will be an exchange of implied obligations or considerations surrounding a change of organs. This applies to almost all organs but I can see the family of a destitute Helicopter Blade victim thinking: well you know, maybe we ought to be taken care of. The potential donor is a very wealthy guy. Why shouldn't our son

help us out? Any place where approval of living individuals is part of the procedure leaves it open to whether that approval will be contingent on some computation. Should the state decide? This I think is a very important policy question, should the state forbid it, allow it, countenance it, enforce contracts based on it and so on?

RG: Well, but coming back to the question of the class thing, Dave drew a very striking kind of problem. But I want to bring us back on this ground. In the initial stages at least until organs are plentiful, and as I said, I would think that might be a long time off, is it feasible or is it appropriate to weight other factors, not skin color, but intellectual achievement or intellectual promise. Lets take that one. You have two people sitting there side by side in a situation where you can either take one guy's or the other guy's liver. Is there somehow you can deal with this issue? [89] One person is a productive, effective scholar, the other is, just to make a wild story, a guy who's a janitor.

? Well, Josh, you check me out on this, but my impression is that this board in Seattle where the kidney machine is set up, in fact, does that sort of thing. Now, I don't think they make their criteria explicit. They have, you know, wise men in the communities somewhat diversified and presumably they reflect the predominant values in the community, and they make judgments. But that their explicit criteria must include things like the worth of the individual, do you know, Josh?

JL: I'll tell you it is a very unhappy experience [in the ground rules of statistics]. Nobody's happy with it and least of all surgeons

there, and I ended up almost in a position, I think, of a psychotherapist because they are so upset about it. I came to the conclusion the only sensible advice I could give them is whatever you do is wrong ..... therefore, why don't you lay out the kinds of people that you would like to treat and whose survival would keep you in operation to the maximum possible extent. If you yourself aren't interested in maintaining these patients and aren't willing to give your all for the particular ones who come through, you aren't going to end up doing the best possible job, and, so, cut the kidding around as to whether there are objectives like socially useful criteria in a thing like this. Exactly the same consideration appears generally to the medical specialties. The surgeon decides which cases he's going to take. Some he does for money, some he does for love. And he loves some people and not others. [106]

Psychiatric care, you know, is notorious for this kind of discrimination and as long as we have a money based society I don't think we can completely turn our backs on that side of the facts about life and death. Don't kid yourselves about it, there are occasions, you know, it's even more or less remote but it is still there. When you have to purchase something it is just more immediately transparent than the financial considerations and the like having to do with availability. We want to minimize it. Certainly we are obliged to even out the grossest discrepancies but I think you'd be kidding yourself if you think you'd ever be able to eliminate them all the way down the line.

RG: But the problem you see, as I understand it, it much more difficult. At Seattle the biggest problem is who goes on the machine. As machines are really limited.

RG: All right, but the transplantation problem is going to get much worse when you get past kidneys because, although there is a financial consideration, there is the absence of having a kidney available from a relative and in some respects there may be more likelihood of getting it in certain lower economic groups where the families are bigger and where there is more apt to be somebody who's willing to do it. When you get to the unpaired organs, then you've really got this decision business for a fare-the-well in a way that you don't have when you are taking a paired organ.

JL: Can't you imagine clubs being formed?  
Something like the community blood reserve we have in Palo Alto?

RG: What do you mean? With respect to unpaired organs?

JL: Yes, a group of people will say if an organ becomes available, if anyone of us reaches a place where one of our organs becomes available, we want first priority for its use to be for another member of this club . . . . .

GG: Even if you put that through in terms of impact you'll get the growth of class discrimination.....[129] as it bears on the hypothetical that Dave was posing in the beginning.

If you go through the scheme like we've been discussing on transplants, you're not likely to be exploiting the Negro, because these schemes are not going to be counting on persuasion of an individual to consent. You're going to be counting on groups like funeral societies, and upon a general consent both of which are likely to be highly upper middle-class oriented phenomena. If you then draw on that basis, you won't be exploiting the poor, but it will also mean that you will be giving very obvious benefits to the middle class access to transplantation.

RG: There's one reason I'm not too deeply worried about it, that is, the skills involved in organ transplantation are still of such a high order you are dealing with the upper crust of American surgery and this has its own ideas about, you know, who ought to get the benefit of their time and experience. You sort of have a large group concerned with a certain level of society as well as the upper class paying patient. These guys as people know when their conscience bothers them if they put \$1000 in their pockets for an operation and then they do one free.

BAM: I'd like to come back. The conversation was kind of turned off in another direction and I'd like to refocus on the question that Bob has raised and consider the same question that Bob Chase was raising yesterday. Given an unpaired organ situation you're not dealing now with an economic problem [149] ----at least not in a very rare case. You would be dealing with an economic problem if the patient himself were to be given the choice. Now, how or what, if anything, does anyone usually say about this one where..... [150-54] Is this the kind of situation you are considering?

RG: Well, this decision is going to have to be made & it's going to be tough under the most ideal circumstances.

[154-56]

[153-55] ?

LB: Let me just relate a story from rather ancient literature which may have slight bearing on this particular issue and that is the story told that two men were stranded on a desert and that there was only enough water for one of them to get home free. Now the question is what should one do with this water. Should one person keep it

and so this one person at least would remain alive or should they divide it and both die? How do you decide which one should keep the water? So in the Talmud, for instance, you find at least one person says that they should divide the water and both of them should die; that is to say, rather than one surviving at the expense of the other. And I think underlying this is the idea that there's an after-life and so that therefore ultimately there won't be any kind of difference. [165?] says that the one who has it has to keep it since it's his, he's under no obligation to give it to the other person, as it were, to commit suicide. And since he has it, the one who has it keeps it. The same example occurs in Stoic literature. And according to the Stoics, they say the one who has the most use should get the water; that is, they have a question of utilitas, and they have a series of priorities as to who is the most useful person for the society. Of course, the one who gets the top priority is the Stoic philosopher. He's the one obviously that decides who's going to get the water and then they have a series of priorities about who else is the most useful for society. And in a certain sense this idea can possibly, have an application here for transplants, that is, a rejection of utilitas because he says that the one man's blood is redder than the other one's so that the one who has it keeps it: He has no obligation to save anyone at the expense of his own life.

JL: Well, did the United States or the Soviet Union give up nuclear bomb? And don't we face this problem all the time?

HLP: How long do you expect the technology to remain in a state in which what you're confronted with is these ad hoc exchanges rather than essentially a banking system?



RG: Oh, well, I think the banking system is quite a way off. Now, the technology for doing for example, renal transplants are trickier, the liver transplants are trickier although there are some around (?) now who do this as a relatively simple procedure. I think it is fair to say that the renal transplant technique is so simple now that it could be done by a lot of different patients? The management of the patients as Josh has suggested, still takes special skills that wouldn't be immediately available. The banking problem, however, I don't think there's anything on the horizon that suggests, I mean I'm sure it will be dealt with, but I think it's a good way off. Wouldn't you agree with that, Josh?

JL: Oh, I think 10 years is a long time in this area and there's likely to be a revolution on our whole outlook [189] on any of these questions over a period of about 10 years?

HLP: I'm wondering how real this exchange problem is. ----

XX: Well, I see the circumstances that disturb you with right now, I'm sorry that Bob isn't here, is on the kidney problem, the question is where do they get or the conditions under which they can accept unrelated donors, they undoubtedly have loosened up in the last few years, you know, from identical twins to biological relatives and now they're reasonably optimistic about doing unrelated donors.

XX: They had a situation that happened pretty spontaneously in Fresno where somebody went on TV and made a plea and 70 unrelated donors, they almost didn't even know who the patient was, at least hadn't known the patient personally. Anyway the interesting thing is for the moment, the surgeon's at Stanford, I believe, have backed off

from this because they are concerned about legal problems. [I believe that's true. I am not really sure [197] ] In other words there is a situation right now when they think they can save a certain number of patients but they are very hesitant to do it for fear that they are going to get into some kind of legal snarl. [200]

JL: Actually, the Colorado group, has used some unrelated donors.

RG: A guy tried do it with prison volunteers who wanted to do it, and that created all kinds of problems.

JL: And now they dropped that. We ought to have some form for coverage of irrevocability in a case like this, that there is some procedure that can protect everybody, you know, like other contracts, so this one really can be made to stick.

RG: You guys know some of the legal business on the kidney transplants have already taken place don't you?  
There are a couple of cases in Boston.

GG: Is that the Massachusetts Advisory opinion that's referred to in the Stanford Law Review comment on human experimentation?

RG: There are all sorts of parameters to this, for example, there is the psychological one. One of the identical twin transplants at Peter Brent Brigham Hospital had one hell of a time because the twin who gave the kidney, did not believe that the other twin was grateful enough. And then he went into a tizzy because he thought 'now if I injure that kidney, I won't have any and can't get one. I don't know all of it but they've had a hell of a time with these people.

I think Josh has a very good point, if you wanted to do something

positive, if you could get into the law some kind of protection, some kind of way in which you could execute this contract and then be free of liability, it would be very important. Because I think this is going to happen more and more as people give up a kidney and then inevitably pile on a -----[214] for example, and a pretty common disease and if you have two kidneys, you at least have some reserve. If you only have one, you can be in bad trouble and I would predict that there is going to be more and more difficulty.

JL: [216] I think it would do the donor some good, too, to know that it was irrevocable in that there was no point in his making any more fuss about it--that he really had signed off. But there has to be obviously a fairly strict procedure to govern that. The questions about whether the consent was informed keep cropping up in medical contexts as in no other area of contract. I am not certain I have the recourse of informed consent when I sign a note at the bank.

GG: [219] The intriguing thing about this case of the minor is, for instance, that the court says in that instance consent alone is not enough, that is, informed consent by the guardians. The court apparently had to satisfy itself that there was some benefit involved and talked about emotional and psychological rewards.

HP: Does that turn on the fact that it was a minor?

GG: Yes.

JL: There was a case in Wisconsin where a sixteen year old was a prospective donor for his older brother and the question was whether he could bring up the question of his being the donor. The legal, moral and the psychiatric conditions cut both ways. If he is prevented from saving his brother's life, he bears a certain kind of

burden. If he had any reluctance to give up the kidney and he is under some pressure to do so he bears a certain kind of burden and so on. I think there is a very serious consideration on how to deal with minor donors.

MF: The thing about the technology comes along and we can start to see the hierarchy. One who donates the kidney should have high priority should he ever need a kidney above all other prospective donees at that particular time, either recognized by the hospital involved or by the state and this might reassure people who gave them.

RG: There is one point though about the kidney that really again is different because of the pairing of the organs. And that is this, that as the technology and as the control of the rejection process is achieved, [237] that is, to a rather fine degree, then you have several options. In the first place, once the kidney is transplanted it may get to the point where a guy has a good prognosis, he is functioning as successfully as he was before; secondly, the business of a re-operation and a second transplant which has already been done can be considered. For example, there is one kind of a renal disease in which transplantation has been done and in which at least initially, (and I suspect that . . . .[241]) the donated kidney became the site of the same disease. This relates to some kind of immunological process. Now, when you get the technology far enough along, it's not really such an incredible business to say, ok, every five years you go and get a new kidney. People do get re-operated for various other things. You wouldn't do it in lieu of or in preference to going to a football game, but you can do it and if the technology is far enough along you really obviate a good many of the problems [246]. There are plenty of people around and if you can control the rejection

business then as a guy needs one, he gets one; and when he needs another one he gets another one: and the guy who gave one up, if he gets to the point where he needs one, then he too gets it. So that situation, although it may be a way off, I think it will ultimately be a relatively simple one to handle. The unpaired organ, again, brings in a whole new series of problems. Inevitably you're never going to have as many organs of the unpaired sort even if you get preservation techniques. [252]

BM: I don't understand about that. And that's what I wanted to ask you about. On the whole, it is still true that there are more people dead than there are alive.

R: Well, one of the reasons is, I personally would believe that many of the organs that you get from people dying, such as hearts and livers, especially hearts, will not be useful because of the degenerative changes that characteristically occur in most persons as they age. Now the kidney thing is different because there you have a constant supply of relatively young kidneys or the kidney can be relatively free of diseased state, although you wouldn't want to, in general, take kidneys from people at let's say 45 or 50 and maybe even less than that. So although there are lots of people dying, obviously, everybody is dying, an awful lot of people who die today are old and of that group, on the basis of facts about pathology, I would say that a lot of them will have hearts that will not be useful.

H: But how many people in a year will need a heart?

RG: Oh, a lot. Coronary artery disease is one of the major causes of death today. the number of deaths from coronary disease, I can't give you but it's a big number.

DH: Can't you imagine that if the technology were far enough along that there would be a demand for preventative replacement of hearts? Just imagine all the symptoms, your [266] [?] changes, you're past 50 and you get a new heart.

BM: But the trouble is where are you going to get them? Do they exist? In some sense this is in some different context from the discussion of yesterday. I have been surprised that the medical people in the discussion have not been pressing more than they have. I have been enormously impressed by what I view as your conservatism about this. I would have thought, given this line of approach, that what you ought to be pounding on the table about, for purposes at least of surfacing this to the public, is that we're going to have to figure out the fastest way we possibly can to start preparing for public acceptance of the notion of having heart banks. We can see the transplantations coming. There is only one real possible source, in fact. And that source has to be essentially young people and that means essentially trauma. And that means that we, in effect, have to get something like what was described as the Swedish collection system going just as fast as we possibly can, with those squads out crawling the highways to pick these people up, because otherwise there is no way in the world we can meet the need and demand.

RG: Well, there is another . . .

JL: Well, that's not going to do it either, Bay. That is why I am seriously concerned about whether we should be embarking on some enterprise in this direction. I really mean it. (BAM: I know) I'm much more conservative than the discussion has reflected here. You are just going to create a state of intense frustration and all the problems that will

come up from just this kind of competition for an extremely scarce resource. The technique will have been established, the demand will have been established by the success of the technique and there just will not begin to be enough to go around.

DH: Another approach that Josh has brought up in another context would be to push very hard for technological solution -- say cross-species transplantation. The least linealogical differences between human species and the others is between us and the chimps, so that you could imagine a [283] huge crash program to breed chimps and, by the way, they are not fully adult until they are 10 years old, so that's not so simple either--but let's say a crash program to breed chimps and solve the problem by transplanting from chimps.

RG: Oh, I don't think there is any question . . .

DH: We'd like to study their behavior, incidentally, if that can be done we'll study them for the first 10 years before they give up their kidneys.

JL: But the steam to fund that kind of thing is to a very considerable extent diverted by the opportunity for transplantation, which is not only regarded as a viable alternative but regarded at the moment as a superior alternative in the case of kidneys. Kidney machines are not regarded as being as good as kidney transplants, and at the present state of technology that is undoubtedly correct. But if there is a misguided view that the problem of sources of kidneys is somehow or another going to be solved, then all the weight is going to be placed on that side of the game, and I don't regard that as wise social policy.

RG: Josh, let me ask you something, just speculating. From what you know about immunology, do you think it is reasonably likely that the problem of avoiding rejection in cross-species transplantations is a practical one?

- JL: Sure, it is. It may require something like prenatal or early post-natal inoculations of infants with <sup>purified antigens</sup> sure pure line [295] or something of that kind, but there's no theoretical difference between this and the cross-species situation -- there is just more [299] at stake and we know less about them. But from another point of view, it may even become easier because as we get genetic control over the species which we're using as donors we get to the point where we know exactly what it is that we have to bump against. We don't know that when we have random individuals.
- RG: Well, as a long term solution certainly that is the most appealing one.
- BM: Heart Funds.
- RG: No, because I think it's what Dave said. Take again the problem of coronary artery disease which is one that ought to be of great interest to everyone around this table because we're the best possible victims.
- DH: After a weekend here.
- RG: Yes. The time to do this in the case of cardiac problems is early, not late. In the case of renal disease you can--I don't know--you might move it up a little if you had the whole thing worked out. In general now, as you know, you wait until people are very near the end of the line to do it. On the other hand, in the case of coronary disease, if you wait very long you're liable to have an episode which makes it unnecessary to think about it anymore. So what Dave was suggesting there that you would want to do it the minute you had any evidence. [306] You really do routine EKG's every six months and the minute you found any change in the tracing you'd probably suggest to somebody, if the technique was perfected, okay, now's the time to go in and get the old pump changed.



JL: You have to take the old one out. It is obviously part of this technology that you have the safety factor of bypass. [309]

RG: All right, but the point is it's like the airlines maintenance business--every so many hours you change the carburetor because when you do that you know the chances are pretty good that the engine isn't going to stop in the middle of the flight. So I think that the number of these would really be substantial in the time you'd like to do them. This would be a preventive maintenance kind of thing.

DH: There is another very closely related line in which Josh has been involved in some activity. This seems to be the point to comment upon it. Instead of an alternate biological machine, the building of a non-biological machine that would do the same tasks: that has all kinds of social ramifications. I think this would be a point, Josh, to say something about that.

JL: Well, the implantable heart pumps still seem some time away. [317]  
Dr. <sup>de Bakker</sup> Bakol (3) has done a few experiments on it with considerable publicity, they simply all flopped. You know, they were given too much publicity. But the fact is that the patients survived a few days after these kinds of implants, the replacement of their own hearts with these machines. The only thing that was wrong with that was it was premature. It's perfectly obvious that that problem is going to be solved. There are lots of difficulties and we're some few years and a couple of billion dollars away from a really comfortable solution on this subject. By and large NIH policy has been not to put very much emphasis on this kind of development. I think they've been influenced by these kinds of attitudes reflected by the transplants and by the feeling that a better understanding of cardiac physiology

and so on would be a more cost effective way to use that kind of investment. I think possibly we realize people are scared about the other implications of an implanted heart because this business of when to pull the plug is going to become that much more acute, the more effective the machine is that plugs you in. So many people reach the point of death now by the fact the heart has stopped and there just isn't anything else anyone can do about it. Presumably that event will no longer be significant as soon as we achieve a certain level of sophistication, the number of effective and marginal decerebrates is just bound to go up. People have had incidents which have affected their brain to the point where their heart was stopped by it, but where this is no longer relevant. I do think there's some fright about on how to deal with that. And that is part of my conservatism, too.

H: Leaving aside the decerebrate problem, I suppose you get a problem of what the tolerable lifespan is.

JL: That's what I meant by marginal decerebrate, he's generally fading away.

H: You don't even have that, if I can leap ahead to that point.

JL: Well, except that without some other technology, there is going to be irremediable decay of cerebral functions. You are going to pass over some threshold at some time. And I don't want to jump to the time when that doesn't happen either.

BM: What kind of a time span did you have in mind for this cerebral decay.

JL: I mean most people show signs of senility starting at about age 20 and it becomes intolerable by age 40 and you sort of hang on until about age 60 or 70, for the most part. Nothing that I've said now has much bearing on that question and that's all I'm talking about.

BM: My own medicological ignorance is such that I just have no notion and intent to which that decay is in some way identifiable as being within the cerebrum or whether it is a function of other kinds of decay that have taken place, so that if you could control in some way the heart collapse [345] or cardio-vascular collapse, then the cerebral process might continue without internally degenerating.

JL: No, just keeping the heart going would not have an awful lot of impact on that process I was just describing. Now, there is a physiology of cerebral aging, a large part of which is vascular, there's no question about that. When you get to the fundamental issue of how to keep the blood vessels from hardening up, then you do approach a fairly significant problem, and one of the points you attack is how to lick this.

RG: And it is being attacked. There are now drugs that presumably may influence the rate at which artero-sclerosis occurs. If you've got, for example, an agent that everyone could tell you to go and get all the calories you want, but take a pill each meal and you wouldn't have to worry about your coronary suffering or your blood vessels, then the whole situation would change again because then people would go on and on. But the real problem of being able to replace the heart as Josh said himself, would not have much effect on cerebral deterioration. As a matter of fact, everybody knows the tragic situation of the people who start going to pot in terms of their intellect and who are hale and hearty, and if you've ever watched this in somebody you knew well and in particular someone who had been a superior individual intellectually and then they start to go down hill . . .

JL: Well, on the contrary, not having the heart stop as a natural termination of the process will aggravate the situation -- this is what I meant by the situation with marginal decerebrates.

RG: That's the point. You simply get more of these people who are hale and hearty as far as their general health is concerned, but whose brains aren't.

BM: It seems to me quite clear that the issue of transplantation and the things that flow from it does get all mixed up with the whole general problem -- the social problem, moral problem [363] tied in with the termination of life. We come to it now, quite directly in a way. What prospect is there, and who is doing any serious thinking about what kind of first efforts are there to rearticulate within the medical profession in an explicit way now, not in some subterranean way, or by lying to yourself, to rearticulate the classic Hippocratic commitment or the classical physician's pattern of action? Or it is simply dictated that your job is essentially to keep "life" going as long as possible. You all know that you are not in fact doing this in lots of situations. You know that the technology that you are now creating will bring more situations in which that is obviously unattractive alternative. -----[370]

JL: Well, the commitment of the physician is not to the life of the patient but to help the patient, first of all; and there isn't necessarily an immediate contradiction to the fact that to give up worrying about the life of a patient when his health is beyond any possible repair. This is essentially the formulation of every doctor I've talked to and how he thinks of it when he is concerned with terminal cases.

H: Health is hard to define though. Take, for example, your marginal decerebrate.

BM: In some senses, at least, he's healthier than he would be if you dropped him down an elevator shaft.

JL: Well, I think though there is just no doubt that nothing like the kind of care is going to be taken at the margin for the guy who is beyond recall with respect to his intellectual function. It will be done by non-feasance rather than misfeasance as you pointed out because of the traditions that surround it, with very, very rare exceptions. Yet there is no doubt that that is quite common. And it may be the most aggressive attack on these questions would be to demand that everyone over the age of 70 shall pass certain performance tests before deciding whether he should continue to live or not.

BM: [380] -----Do you find that as a member of the medical profession you find it more comfortable to have the doctors decide.

JL: Not really having the doctors decide. The value placed on the aged individual is something which is in fact shared by the rest of the community and I think, again, a physician dealing with the situation is going to inquire what impact that individual has on his family and so on in deciding about this. If it is very obvious that every member of the family in a rather healthy way finds great utility from their contact with this aged individual as limited as that contact is, the doctor is going to be pushed by them and he himself will want to take a more aggressive role in keeping the patient going than would be the case otherwise. Am I wrong in that connection, Bob? [389]

RG: No, but there is a social judgment connected with it.

BM: But there is also a question of who decides.

LB: A few days ago, Bob Chase brought up the question whether the function of the doctor was to save the patient's life or help the patient. There is ambiguity in whatever it means to help the patient; in certain circumstances this would mean to really help them out. This would be better for the family. This question of the definition of exactly what the doctor's function really is is summed up by what you mentioned very briefly--the question of saving or helping and what is the meaning of helping and in what specific circumstances you would help a person by terminating him.

MN: It seems to me that there is a prior problem underlying this, and I don't know even how you address it but I'm not sure what right we have to be so committed as we are to technological progress. That is to say, when an enormous number of people--and this really extends to that earlier point -- haven't even minimum medical care, I'm wondering if we're not doing something really absurd in the direction of our medicine which basically helps a very small portion of the world and even a small proportion of our own society. Consequently we get stuck when we talk about social utility and the values in the community, we're really talking about the values of a very small portion of the community and we're defining society in a very narrow way. It's not a world society we're thinking of. We're thinking at best of an American society and in that society, we're thinking chiefly of social leaders, who are the affluent, the professionals. So it seems to me that this is one of the reasons why we are coming to a deadend here. The emphasis on technological progress makes it easier to keep a certain class of Americans, basically, alive for almost preposterous lengths while minimal standards in other places are very sad. And I just wondered if the social

question really isn't terribly fundamental and it would call for a great reallocation of resources and priorities.

RG: Well, you're not suggesting we take the resources that, for example, what you're saying, as I understand it, is given X number of dollars, rather than put these dollars in on research, we ought to just say, ok, we're going to now try to apply what we already know to the population on a broader scale, we're not going to carry forward this research.

MN: Yes, we could at least consider that and decide, you know, which allocation goes where.

RG: But you see, if 10 years ago, or 12 years ago, that position had been taken, then the prevention of polio which is today a totally feasible goal anywhere, would never have come about and we would have continued to have lots of people having polio or a certain number of people having polio. Now, this question of reallocation of resources--I don't think it can be looked at in connection with the reallocation of resources that are presently going into medical research. If you want to extend it and say we ought to reallocate the money we're putting into military spending, 415 lots of us, but not everyone here would say I would agree with you, that would be great. But I think it's very dangerous to--although your objectives are ones with which we are all obviously sympathetic--I don't think the answer is to stop doing the research. Now we might want to put research into some other areas or to reorient certain kinds of our research, perhaps in the case, for example, of the transplantation, maybe what we ought to do is allocate--the resources are never unlimited--perhaps what we ought to do is allocate more towards this cross species business, than to the present effort, recognizing that the long run goal is a more important one, than the immediate short term gains.

BM: But notice that in some senses that proposal goes in exactly the opposite direction. You're directing your research money towards a more remote possibilities.

MN: Well, there is something else I'm reaching for and I don't know if I can put my finger on it, but there is a way in which the commitment can be given increasingly to technological advance rather than anything else. And, in fact, organs become more significant than human beings. I grant that, especially up to the present, research has broadened the possibilities of larger numbers of human beings getting over basic diseases that could not have been gotten over before. One of our problems is that we've been so well on stopping these diseases that overpopulation and the rest of it troubles us. But, I wonder, is this a legitimate rule for all times that it becomes sort of an absolute that we continue putting as large a share of our resources, even our medical resources, as we now do, into research, presumably forever more refined standards of health of certain organs, while large numbers of people aren't even over the basic hump. In other words, I agree that this is really a national problem fundamentally of allocation of all national resources, not specifically medical resources. But it may even be a more limited scale of a question of medical resources, too.

JL: I think that's a legitimate question and I think it is one you've already answered in your own mind in so far as you are at Stanford University rather than teaching high school in a little back country village somewhere. This is exactly the same question that applies to problems of capital investments for long term ends or any kind of an elite activity. [436] It obviously can be pushed to the point of absurdity in either direction. I think it is easy to prove that the expectations of even



the average number of our posterity would be greatly hindered by this kind of allocation of resources. It's also easy to point out that some absurdities may be encountered. . . .[439]

MN: No, I'm sure of that, but it's a question of judgment, that there is no clear line on either side. But I do think it is a question that ought to be raised even at this kind of discussion because of the fact we brought up earlier that at this point in time, the beneficiaries are going to be pretty well class differentiated. In your remarks a little while ago you talked about the inevitability of this as long as the American Society is the way it is. But I wonder ought medicine to, as it were, reinforce those standards, or ought it not to some degree keep challenging them. I guess you can say to some degree it does.

BM: Could I speak sort of on your own behalf and give you my impression from one of the points you made. I thought you were making two points.[448] One had to do with the matter of reallocation. [449] The other one really is sort of an assertion of the development of a kind of a moral problem. It comes in to the extent to which the research man really does become more interested, leaving aside the question of allocation in the pursuit of the technology for the sake of the pursuit of the technology, increasingly losing sight of, (this is the allegation) the use to which the technology will be put, that is, saving human lives. Both points are there and half, I think, is meetable, but the other half it seems to me, to be a very real and difficult moral question.

JL: I think I raised it myself. [494] The pursuit of organ transplantation does reflect some of that. It is a little more obvious that it is possible now, and so it is being more aggressively pursued than I believe the long range view of the matter suggests doing. I'm suggesting different timing. . . .[456]?

MN: Well, actually a lot of people have made this point in some way or other, and it just kept accumulating up in mind. It is a basic issue that should be brought out specifically.

JL: Well, I want to distinguish between the research side of it and the deployment side of it. And I would tenaciously argue against any limitation on the investigative aspect to find out more and more. Without that [459] we can never achieve a mastery of nature and we have innumerable enemies of health, happiness, the maintenance of our lives and our dignity as human beings that require that kind of mastery over nature which we can never achieve without this kind of search about ever widening frontiers.

MN: Josh, what I am questioning though really is that assertion. I wonder if at some point, after you achieve a certain limit, the problem shifts. In other words, I am not convinced about what you said that our problem is the mastery of nature. In fact, we've accumulated lots of more human problems on a less remote level than that, which if we keep bypassing to attack nature . . . .

JL: Well, our understanding of those problems is part of research too. The investigation of the kinds of considerations that lead to this pathology and so on are part of the *problem*. In any case, that type of investigation involves a commitment of only a small part of overall resources. It is really essentially a question of deployment, whether you are going to manufacture them. And here I think there are very serious questions at the level of expense in what you raise. Are we making the right deployment? It is perfectly obvious that if we drain off most of our deployment energies to use the newest technologies, it is legitimate to bring other uses into the arena as a competitor to investments in top technologies.

RG: I agree completely with that, but I do think that the directions of research talent are socially conditioned; and research talent is a very scarce commodity. If there's some dilemma here--it seems to me that in general the medical problem of the more technologically advanced society is on the whole quite different from the technologically underdeveloped societies; it overlaps, but problems of malnutrition and malaria and so on, the tropical diseases, prenatal and paranatal care, those issues are the primary ones in the technologically underdeveloped countries and that's not so here. Now to some extent it's a question of straight application of what we now know. But on the other hand, I suspect a good deal of it would depend on research, to have more efficient solutions to these problems than we now have. When the societies with the scarce talent were, for instance, pulled into areas of the world where malaria was prevalent, you did get during the war a burst of research on malaria, and I think it is probably correct to say that a large part of what now is done throughout the world is a function of what some American and other Western scientists did during World War II. Now, today, my impression is that the amount of research on malaria sponsored in the U.S., Britain, Sweden, and so forth, where the research talent is, is probably very small indeed. It is not terribly pressing. . .

JL: That's quite apart from the last year or two on account of Viet Nam.

BM: You may have just advanced the best argument for our being in Viet Nam.

MN: There is bound to be some good flow from it. It can't be all bad.

JL: The trouble with that kind of remark you make is that it is made often enough. It tends to be heard without sufficient discrimination and finesse. I get it back from lots of Congressmen [490] and it just ends up as a sort of vaguely stated, rather foggy remark "well, maybe

ends up as a sort of vaguely stated, rather foggy remark "well, maybe we're doing enough research. We don't have to do any more." That's why I am so concerned about that kind of misunderstanding.

DH: There is another implication in Michael's remark which obviously I would back very strongly. If you ask what are the contemporary problems of most technologically advanced societies, they are in very substantial part the problems of interhuman relationships. I would argue that we do not for a moment understand enough so that it is a question of straight application, so that we know what to do. I think there is a important need of research in human sciences, if you like, to try to understand the nature of the beast more. This is some shift in emphasis, which I believe has been actually taking place in the last few years and I'd like to abet it.

MN: I would like to move down that alley some more. First, I was trying to raise the question of commitment toward technological research in the context of the sorts of things we have been discussing, keeping certain kinds of people alive at certain stages in their development. I seemed to me a limited sample of people in this country as against people all over the world. One of the questions is to what extent are we committed to this particular kind of technological research? But other questions would be where else would we use the resources. We might want to go in the directions of the diseases of the underdeveloped countries or in a more mundane type of social medicine. Or much more on an applicational level, how do you go about bringing up standards of hospitals and clinics and so forth in these countries where they barely exist. That would be such a much lower level of research, but I don't think we know very much about it and how to do it.

- DH: Bob Glaser's point earlier I think is a very good one, where if you take polio, I spent a good part of my time for several years working on one of those polio foundation-sponsored units with severe polio cases and maximum effort at rehabilitation. It was very poignant because during that time the vaccine became feasible and it made a very profound impression on me. If you take that kind of an example as a model and think of the resources we could pour into trying to help out the polio situation, throughout the world in underdeveloped countries pre-vaccine, and how much more feasible and effective is the solution that came out of what at one time would have said to have been basic research of a very impractical character and remote from the immediate problems of those suffering Africans who have polio. I think there are probably a lot of examples like this.
- RG: Just the money it would have taken to keep 10 polio, really seriously handicapped victims, alive in a custodial situation would probably provide for the prevention of polio in literally thousands and thousands of people. Take the Viet Nam situation right now. The billions we're pouring into Viet Nam, something like 20-30 billion dollars a year. Twenty to thirty billion dollars would make it possible to do something about the water supply. One of the problems that really confronts them, and really contributes to the massive cases of cholera is the fact that there is no water supply that is safe to drink. Now, obviously, it is more difficult to do this in a wartorn country, than in one that isn't. But nonetheless, the order of magnitude of the investment that would accomplish a lot of improvement by several orders of magnitude, [522] for lot of them, it is not a huge amount of money. I think the real difficulty is that the expenditures in the military effort are really the megabuck kind, but

we're talking about really the application of health methods are much closer to the microbuck kind for many of these things. And as I understand it, one of the reasons the Russians have been so successful is that they have improved the standards of living in a lot of the areas in Russia, apparently, by simply applying a very simple fundamental known facts, in the public health area, not very sophisticated but they're not worried about Renal transplants in these far away areas but they have changed the whole character of things with the water purification, small pox vaccine, and so forth.

JL: Renal transplants sound very sophisticated, almost exotic now. Certainly sepsis in the course of surgery must have seemed like that at the time it was introduced. I think we could make the same arguments about the nature of dissemination of care around 1900 and we would still be trying hard to get an equality of access to those standards today. Trying to solve those problems without an elite to point the way, to set standards, to build possibilities, and to find better ways of doing exactly that you are concerned about, like the massive attack on development of a polio vaccine doesn't get you anywhere at all. There is just no simplistic answer to this question. There is also still a payoff accomplished by present investment in research, even of the most esoteric kind. In an unsuspected way one of the by-products of science and technology today is the answer for tomorrow--and you aren't going to have it for tomorrow if you don't do it today.

RG: A marvelous example is Phenylketonuria. Here is information that came out of fairly fundamental research that really has altered dramatically the situation with respect to a disease which it was possible for a fairly significant number of people to contract. It was based upon an inability of [ ? ] an amino acid, in a proper way and they become

mentally retarded. When I was a medical student this was an absolute curiosity and nobody knew anything about it. Let's face it, in relatively few years, by virtue of better understanding, it is possible to pick this up before there is any brain damage, to put these children on synthetic diets, to prevent this mental retardation. Again the enormous cost of custodial care which we often lose sight of, even lousy custodial care, which we have in our state hospitals, is enormous.

JL: Bob, it is undoubtedly true that the equivalent amount of attention to more generous problems of malnutrition in Mississippi for example, would have a large payoff. We don't quite know how to administer that amount of attention in that situation. Paradoxically, Phenylketonuria [546] does focus attention on problems of infant nutrition. It generates a certain amount of research on infant diets. It gets the background to at least deal better with malnutrition.

RG: The cost of the advance in the understanding of Phenylketonuria was very small, if you look at it.

JL: Well, I'm not talking about the research end of it but the management, you know, of the special diets, the testing and that kind of thing, which is expensive.

RG: But the problem is that 50 years ago if somebody would have said this is a problem that is going to be controlled by a very simple little procedure that you can do on any newborn and that you can prevent the disease simply by synthetic diets--and it is not that expensive or complicated a thing, it would have seemed unbelievable. The problem is we don't know, and the thing we have got to find out is how many other things are in that category, and we can't stop doing that. At the same time we do have this terrible problem of applying the information we do have and the knowledge we do have to the betterment of all.

MN: I think we are discussing social medicine. At least one of the cutting edges is this social dimension that I'm talking about. [554] Granted there is another edge which is the one we have been interested in, and I do think the other one needs to be mentioned. I think that some of the unease that has been voiced about Hippocratic oath would be alleviated by this social dimension. In other words, medicine in a technological age has, it seems to me, a different set or a more complicated set of responsibilities towards human health and it requires, in fact, the kind of social cutting edge. When you think about public utilities, you can't really accept the given value but if we're going to live in a society that puts that much money into bonds and the rest of it, and it seems to me the doctor is in one of the positions where he has got to be leading community values rather than merely following in the name of his own medicine.

LB: Well, I think in general here the problem we are faced with now is [561] the question of ends and means and exactly which ends. There is a total goal and a subordinate goal and the question is which goal should be subordinate to which goal. For instance, what is the end, what is the goal of the physician and how can he achieve that end? For instance, start out with the question of transplants. At the end is saving human lives by terminating as it were human life. This is a little bit different so it opens up the whole dialectic of saving life by terminating life and the question: which lives are you going to save? And this is something which we really could just think about. We've talked about it but it's something that is not really spelled out 100% clearly. We have the question of deployment versus research and then which deployment and where--deployment in the United States, the whole world, or which area?

BM: The law side has been maintaining an unwonted silence this morning.



JL: Could I ask for comments on some specific legal question which has to do with the traffic in organs. I have laid out the problem. There is a potential of transactions and to what extent should there be law governing these.

HP: What's wrong with the free market hypothesis?

JL: Well, do you contemplate the law enforcing these contracts in this area, including specific performance?

HP: Yes, bringing to bear all the doctrines that we have on duress. It must be a voluntary undertaking.

BM: What about specific performance?

JL: Shakespeare took care of one aspect of this in the Merchant of Venice. Can an individual contract to deliver one kidney at a specified date in the future with complete knowledge of the risks involved in the undertaking and receive what might be generally regarded as appropriate compensation and could he then be obliged to perform?

BM: And after you've answered that one let's try it on the heart.

JL: Well, there I think some special reservations would come to play. I think most judges and juries would say that a man could not legally offer his life. There are certain social policy considerations. That is all very well ingrained, I think.

HP: Well, starting at the small end of the problem, I don't see any difficulty at all about enforcing a contract against someone who has agreed that if at some time in the future I become decerebrate, you may remove this or that organ.

JL: OK, in this somewhat helpless situation . . . (?) [587]

GG: The very fact of the decerebration makes it an easy problem. In a sense we have been talking about the easier problems when we've been talking

about the transplant from the decerebrate--the fellow who is nearly dead in any event. The kidney and the human experimentation really present the harder problem. It partly concerns the ultimate enforceability of contracts and partly concerns how much information you need to show freely given consent side so that it will stand up.

JL: Well, the consent aspects for taking a kidney out are on contemporary experience is not too uncertain. There are many other areas of experimentation where there is greater uncertainty than giving up the kidney. There may be a kind of squeamishness.

GG: The kidney transplant situation becomes an easier one than those we've talked about simply because of experience. As you move closer to the frontiers of experimentation, I suspect you'll have difficulties of experimentation, your difficulties may become greater because you don't know much about what's going to happen.

JL: Can you think of any analogs as to what squeamish things people can obligate themselves and remain obligated?

I am asking for some history, some experience on these kinds of things.

GG: Well, the thing that kicked this experimentation discussion off was the very fact that you had a very squeamish reaction to the injection of live cancer cells even though the risks were very limited, and in fact no harm actually resulted.

JL: Can individuals contract to form pacts such that would be generally regarded as being extremely self humiliating although not in any material sense injurious? That would be the closest kind of analog I could think of.

BM: You picked one of the sub-problems yourself, Josh, in the way you put your first question. One of the things that makes it difficult for lawyers to respond is the way the law has developed. It is so very difficult to get specific performance of a contract. The law has just rarely contemplated -- with exceptions, of course, -- the fundamental jurisprudential notion that the engines of the society and its legal institutions would seriously go into the business of trying to enforce contracts. They just have never done that. The classical articulation whether one agrees with it or not [609] is that you do not have to perform contracts. The law has given to you at all times the option either of performing it or responding to damages. And therefore, except in certain special cases -- most obviously matters involving unique goods, even then only limited cases, the law has fought off the notion of specifically enforcing anything. Therefore the reason, I think, you get a general silence on what kinds of analogues there are is because the case doesn't come out. Of course, you can take the one case where you enter a contract and specifically undertake to accept the judgment for specific performance.

MF: If I sell short on some stock, how far against the wall can I find myself on the doctrine of specific performance? [615]

BM: The simple, flat answer is we could design some bizarre situation or some unique situation, but we would have to work at it to do it. The short-hand answer is you don't have to perform it at all, but it is going to cost you a lot of money.

JL: How are the damages going to be assessed? In terms of what it cost to buy the stock on the market?

MF: Can I sell short for a buck and lose a million?

BM: Right--exactly. But this is why when you really come to the area of so-called specific performance of contracts, the issue is not in fact specific performance. What it is really about is all kinds of techniques and methods, aligned with speculation on how to make estimates about damage. It all turns into a damage analysis, and that is where the focus always is.

JL: Well, if my life depends on your specific performance of letting me have a kidney, the damages are really very, very large.

BM: That is right. But that would be far more the way the argument would come out when actually brought to the legal context than whether or not you could really make the guy pony up the kidney.

HP: Have we had any experience with contracts to perform specifically?

BM: I only know of one and it hasn't worked. It is the matter of commitment, and it is a poor example because it is so close to the money market. It is not infrequent to get loan agreements where the actual commitment is to borrow the money. The statement really is, I am going to borrow it--and the guy doesn't take the money because obviously the market fall apart. The courts nearly always say give him damages. But you're so close to the money market anyway.

MF: Here's one, but it is not pure. It's the case of someone who buys furniture on time with a contractual provision that if I ever default on the contract you can come and get your furniture back. Answer: You can come and get your furniture peacefully but if I stand in the doorway you can't push me out of the way to take your furniture back. Then you have to go to court; you can't enforce your contract to get your furniture back. There are occasions in which other social considerations will intervene to prevent even enforcement of freely bargained for conditions of that sort.

- JL: While selling short strikes me as almost the classic instance of this sort, I am not sure as a practical matter how far that will go.
- HP: Damages is money and you have an adequate remedy. If you have an adequate remedy, specific performance doesn't mean a thing.
- BM: Really, a much closer cases than the ones you have been worrying about is the agreement to get someone the Hope diamond because in that case you are going to get the particular thing you want. Then you don't give him the Hope diamond and you'll respond with damages--which won't do him any good.
- HP: How about a contract to sell the controlling shares in a corporation?
- BM: Well, I was going to shift to that or something very close to that one. The one area in which you probably, [638] you can begin to see something like specific performance will relate to the unique power control of a corporation where the agreement is not selling short but to vote stock in a particular way. Even then [ ] you have special statutory action and by and large the court responds, "Boy, we just don't want to get involved in that. You tell us how much you hurt and we will work out some way to get you compensated."
- JL: Well, if I sell a stock short, the guy I sold it to doesn't get hurt when I don't deliver, then the only thing he loses is the chance to get my skin.
- BM: He can always buy more. That is not really a very good example.
- JL: I can see the situation where he owns all the stock. Because there is not any other market because he bought it all up -- which is the traditional way of manipulating the market price. How far can you go? I mean what price is he able to set on that stock so that I can discharge my contractual responsibility? I suppose this is an arena where I can answer my own questions in a certain way. This is an arena where the

risks of this kind of manipulation are well known to both parties who go into it. And anyone who goes into it does so at his own peril, knowing the possibility that he may get caught on this and, of course, someone may put a high evaluation on that last share of stock.

BM: Where could you get a specific performance. Well let's just for a very quick review purpose try to articulate it. There is a general area of land transfers which the courts have been willing to step in and say, if you say you are going to sell that piece of land, then it is that piece of land which you must sell and we will enforce it. If you go beyond there, you have the Hope diamond case, the specific chattel.

MF: I take it the kidney is not that kind of situation. I can go out on the market now and find out how much it would cost me to buy a comparable kidney and bill you the difference.

GG: What about the brother's kidney?

MF: If the kidney acquires some uniqueness, then maybe specific performance makes sense.

BM: All I wanted to do about the series of questions was to illustrate first of all how much we have to claw for the answer. Second, the criterion that emerges is: can you really make out the case that in a particular circumstance the item that is involved in the transaction is particularly unique.

HP: Of course the strongest case or some of the strongest language we have against specific performance is in the personal service contract which is essentially what we are talking about. We will make Madam Wagner respond to damages, but we won't make her sing.

MF: It is quite clear also that if her contract had included a provision saying that, if at any time I violate it, you get specific performance, that would be what you would have gotten.

JL: I didn't realize there was this conservatism.

HP: It comes very close to voluntary servitude.

BM: And also the courts are wary about the administerability of it. You can make Madam Wagner get on the stage, but you can't make her hit an A sharp.

MF: Yes, but on the other hand, that does not apply to kidneys.

HP: But then you've got the whole business of knocking him down or tying him up and carting him screaming to the hospital.

JL: But most contracts forbid you go sing for anybody else.

BM: Exactly. But that is another matter.

HP: But here it kind of breaks down. You don't want to give your kidney for A, you want to give it for B . . . . .

BM: I've committed myself to give it to you, but now I find out that my sister is also ill now and I am not going to give it to you.

MF: Are there social reasons why you might want to forbid a market in kidneys just like you don't want to have a market for military service.

JL: No, I think it is the concept of involuntary servitude which is behind it. You are providing for a unique kind of service and the possibilities of its abuse are enormous. [666]

MF: There is a subtle form of social duress in that poorer people will be more willing and desirous of selling their kidneys than wealthy people, so you would be getting kidneys from a particular class of people.

HP: Of course we have got that with blood now.

MF: Well, I think that is right. That's why I am wondering why there is any concern. Are kidneys different from blood?

JL: Well, I guess my making a remark is based on some small reservations about the safety of giving up a kidney. You have limited your life to some extent. You don't really know how much. But there may come a time when

a kidney is very much like blood. If you are in difficulty, you can buy another one yourself.

BM: At the same time, if I understand your question, you do not want to go into the unpaired organs. The question wasn't directed at that.

JL: No, it wasn't. I assumed that on the question of explicitly contracting to give up one's life we already have sufficient tradition.

BM: Do we? We call it enlistment if you are going into the military.

JL: That is an interesting question. I think that in most circumstances -- individuals are rarely obliged to go into a ordinary situation expecting death, that is, where the ordinary outcome of that situation is that they will be dead. [674]. . .

GG: Well, you can get beyond the blood situation in terms of relative danger and also relative squeamishness to how common or uncommon it is. In the criminal procedure area we draw lines explicitly in terms of notions of decency or civilized behavior between blood tests and using more unusual and more obvious and less routine invasions of the body, and the law responds in that area. It's response could be different than it would be in the area of specific performance. 679

JL: Well, I guess my squeamishness about a market in organs will certainly open questions that Dave mentioned. There is no question in what direction we would go in terms of the source of organs by class. This in turn is likely to arouse some of the many grievances about the impact of that economic differential. The difference in income really does mean who gets the chance for use of the techniques and so forth. It will have a kind of impact on people's class consciousness. That is not a very strong argument and there is no rational basis for it. [684]

HP: Turn it around and ask if we can forbid compensation.



- JL: Well that is the only way to prevent a market is to forbid compensation.
- BM: But it is one of the sure ways to create a market.
- HP: Yes, it certainly is.
- JL: A black market you mean.
- HP: Sure. Anything people want badly enough, they will develop a market for it.
- JL: It is much easier to discover this kind of black market and you would have much greater success eliminating this kind of black market than you would most others.
- HP: I don't know. You get side agreement. I mean, how are you going to get someone in in the first place?
- JL: Well, that is where the law comes in. Will it in fact enforce payment? If I have given up my organ in consideration for a promise of a certain number of dollars, will I be able to collect? Can I use the courts to help collect?
- HP: And presumably you won't, word gets around and the number of "voluntary" donors drops down to zero.
- BM: On the other hand, I can see the development of a kind of multi-service social center just across the Mexican border. You have divorces, pot and livers.
- JL: Well, I was going to raise the international market next because the intensification of this class discrimination gets that much greater between the developed and the developing countries. In a sense we are right back to Swift's Modest Proposal.
- BM: As I run my mind around other areas in which we have sought to regulate markets--not all with respect to the so-called money economy, the basic question is of allocating resources for which you have a heavy demand

and a limited supply. Some kind of a market will emerge, whether it is paid off in dollars or something else. It will be paid off in something, emerging from the demand-supply differential. What administrative process in any society going to design to control, regulate or obliterate that process. I am honestly inclined to believe that the answer to your question is that we are not going to be able to head it off.

JL: The baby market I think, although there is no longer the degree of difficulty. But it is not a bad analogue. I don't mean in Swift's sense, but I mean for adoption. The point of application for social control is the registration of the adoption per se--that is, you have to show evidence of legitimate procurement of the baby before you can go ahead and adopt. And this is where it is possible to scrutinize the process by which the baby has been obtained. I can conceive that this same standard might be adopted with respect to heart transplants. Every transplantation of a vital organ would have to be registered and some reasonably verifiable identification of the source of the organ would have to be made. It would be possible to control that market if there was a decision to do so.

BM: You have one major advantage here--not so much in the strong demand side, but on the supply side. Transplantation requires such highly sophisticated equipment. There are such a limited number of centers where the extraction can take place.

JL: Well that might be done in a clandestine way but it is unlikely that the real transplantation will be done in a clandestine way. Extraction could be covered up in another place or country.

RG: Well, except that the problem at least at the present state of knowledge requires the maintenancy of the integrity of the organ to be transplanted. You have got to do it relatively rapidly even in the dog lab. Now, maybe we can learn how to get over this.

JL: We'll come to a organ bank situation. [709] I don't think it presents a very serious technological problem over several days provided the organ can be taken out at the right time. [710] It really is not unthinkable that we can have organs extracted in Mexico just across the border.

BM: Doesn't all of this suggest that the general tack of the crude statutory approach which we were wrestling with yesterday, coupled with Josh's suggestion about seeking other technological ways -- the heart pump and the heart farm are really in the long run more promising and less explosive socially than the removal of organs from living persons granting your point that the supply will still never be large enough, particularly in unpaired organs? Aren't we always going to be driven to the cadaver or the just about to become cadaver?

HP: You are certainly going to have an awful lot of pressure on your technology to bridge the existing gap and get over it.

JL: Well I think you have got to distinguish very carefully between hearts and kidneys--I mean the paired and unpaired organs are very different.

RG: The kidney one I do not really think is going to be a major problem as technology advances.

JL: Well it is a different set of problems, but it is going to come from living donors.

RG: Well, the better the technique gets, the less the problem gets because then there isn't the same risk of giving a kidney. If you knew that by giving a kidney to someone in the family you were not really compromising yourself for the simple reason that when you needed one one would undoubtedly be available. There are twice as many kidneys as people.

JL: Almost, not exactly twice.

RG: There is a lot more supply than demand so that that one is in a special

category. The real problem is in unpaired organs. Josh, wouldn't you agree that if we can lick the cross-species problem, then the supply problem is not going to be difficult.

JL: Obviously . . . .

HP: When you've licked the rejection problem, I think that's what you call it, within the species so that anybody can give a kidney to anybody, isn't it perfectly clear that there is going to develop a market in kidneys once you break the familial nexus which is what you need now.

JL: There is a market now. Whether there are cash transactions or not. There are certainly conversations . . .

HP: Well, I mean in the more conventional sense.

RG: Well, there are some exceptions, but by and large it is going to be possible to do it within families.

BM: Well, on that very point--can you explain something I did not understand a few moments ago when you said doctors were afraid on legal grounds to move outside the family environment to unrelated donors. I understand that there is a problem. But I don't see that the problem is any greater or less in the case of the related donor from the case of the unrelated donor.

JL: Probably it isn't but the hope, unrealistic hope that if it is within the family, the matter is more likely to be settled without litigation.

BM: Well, don't ever talk to a lawyer about that. In principle I would offer you the view that unrelated people are less apt to see each other in court than are related people.

DH: There is also the point that Gerry mentioned earlier--some kind of doctrine of positive benefit to the donor, or at least the prevention of future harm to the donor, that is, how guilty he would feel if he hadn't given the

kidney to his brother and his brother died. Some people were worried that in the case of the unrelated donor there wouldn't be that kind of feeling, and for that reason, the surgeons asked us to look at a few cases. David Dorson in our department followed all of the potential donors he could get his hands on, is still following a number of them. The surgeons were interested in this procedure before they backed off temporarily. And one very clear thing that came out--that is, that for many of these unrelated donors or potential donors there was a strong element of the sense of personal worth that would be embedded in the act of giving a kidney. It would make me a better person in some way if I can do this. Well, then the issue comes up, how would that survive the failure of the transplant? Now you get terrific reactions. One of the problems we worried about, and its plausible that they were, was that when the person finds out the thing didn't take--that his kidney was wasted and there would be some kind of betrayal involved. But even following up on that point interestingly enough on the few cases they have done, [741] even when the transplant did fail, the experience so far is that the person's psychological formulation of it was something like the deed itself made me a better person. At least on a time scale of a year or so it seems to have some enduring significance for most [743] people along that line. There is a whole issue of personal worth in relation to giving an organ. Even in the organ society on the funeral society model case, I think it presents an interesting situation.

RG: At a lower level the business of donating blood, there are a lot of people who donate blood and get a great feeling about the part that they play. Of course they dramatize it. It might come to the point in utilizing unrelated donors in the long run that you do it on the same basis that you

use sperm from somebody for artificial insemination. You do this on an anonymous basis so that you never get into the issue of what happened to it.

BM: What is the underlying argument--that question flickered across my mind when someone else made reference to close identification and also when Josh suggested registration--what is the argument in favor of building up a record that permits that kind of tracing? I think it may raise far more problems than it solves. Why isn't the anonymity of the blood transfusion and the anonymity of the sperm bank, a preferable way to go?

RG: Well, for the blood transfusion, there is anonymity there in one degree simply in the first place because the volume of blood used and the magnitude of the operation. On the other hand, you can always go back and trace where blood came from which is important, for example, in the case of hepatitis. That is, if hepatitis develops, you want to know who the potential donor was.

MF: I can't go back. You won't tell me who got my blood. But you can find out by following through the blood records?

RC: I agree, but then we might come back to you and say you ought not to be a donor again. [754]

JL: There is no formal anonymity in the case of blood. [754]

RG: No, and nobody would really worry about it. As a matter of fact, there are probably still situations where blood is collected from particularly rare or less common donors for a specific case. You see this in the newspaper where a [755] heart case needs blood, and people go in and they know whom their blood is going to. There's no problem, as far as I know, developing from it. [756]

MF: But in the kidney, it's inevitable now because there have been so few.

JL: I think adoption may be the best analogue for the argument I would raise on this point. I think it probably desirable that there be a kind of anonymity when unrelated donors are used. It just makes the matter less complicated if we don't introduce the question of personal relationships between the people. On the other hand, just as in adoption, I think there is an interest at stake in maintaining regularity of the proceedings, to prevent the establishment of a market in babies. It seems to me one could have a system of registration exactly analogous to that in adoption. [761] The documents certifying the source and the fate of certain kinds of organs would be deposited with the coroner or the county clerk and they be sealed. They would be protected from anyone except investigating authorities. The only purpose is to make it possible to ensure there has not been any abuse of a potential market and to help it from ever getting started. Now is the time to set up that kind of registration so that we don't get a tradition of an established market. . . . [764]

GG: Well, you could have that without tracing the [765]-individual organ. You could have it at the input point.

JL: [766] Well, you could have that. It could be at the point of deposit into a bank rather than implantation in the individual where certification takes place. I think the place of most obvious supervision is at the implantation site, and to that extent, I think the registration of the operation for transplant would probably be the easiest to report.

GG: The case of tracing goes back to the kind of consideration of the point that Dave made. In a particularly risky kind of transplantation you may want to have a means of showing the donor the psychological reward you'd get from donating to a particular person rather than to the world at large to justify his estimate of worth. 770

JL: Well, I think there is nothing that prevents you from communicating that information. It is just that the law should not require it. The law should provide a procedure for anonymity. It is not a crime to divulge the name of the mother of an adopted child. It is just not done as part of the normal proceedings.

RG: There is one other interesting point. It comes up occasionally--at least one thinks of it occasionally--and that is the problem with respect to the donor. For he must undergo an operation in order to donate his kidney. Now it happens to be an interesting fact that although there is a mortality rate associated with any anesthetic procedure [775] there hasn't to date been recorded a death in a donor. But it is a very interesting problem for a lot of these transplant guys as to what happens to Joe Blow, who is a healthy 24 year old guy, comes in and tries to give his kidney to his brother or maybe his mother, and dies either under the anesthetic or something that is obviously attributable to the procedure. Now he signs an operative permit again; you get into the area of informed consent and the point we talked about before, namely, whether it really is informed consent, when you undergo a surgical procedure because most people couldn't possibly outline all the potential dangers there.

BM: Why do you say that, Bob? If you mean it medicalologically, that you couldn't explain all the possible particulars that might be involved, of course you are right. But can't you take this particular point and say, well, N percent of any people who get involved in this procedure die and that there is some risk there?

RG: Have you ever had an operation?

BM: Yes.

RG: Were you ever told that. Did you see that in a release you signed in the hospital?



BM: No, I guess I know it.

RG: Well, as an intellectual you know it. But the facts are that 99.9 percent of the patients who undergo an operation sign a release which even if they read it doesn't tell them anything about the dangers. Furthermore you've got this problem. Suppose you've got a lady who is 45 years old who needs her gall bladder out. Now, if you say to this lady, you understand that when you come into this hospital there is a risk, albeit a small one, that you are going to die under the anesthetic, that you may get trauma phlebitis and a coronary embolism and die, or this, that or the other thing.

GG: But you are under higher obligation to inform in this area than even under this therapeutic situation. The kidney transplant situation where if you thought the donor was not about to benefit other than in psychological rewards is precisely the kind of situation where you should have probably a lower risk situation than a lot of experimental drugs and experimental operations . . .[789]

JL: There is a very simple procedure for this, and it just ought to be done anyhow. It is insurance. I mean, anybody who undergoes this kind of procedure ought to be insured for a couple hundred thousand, a half million or a million dollars against such an event.

BM: You think you can buy that insurance?

JL: You do it yourself there and the cost of this should be spread out over all the cases.

BM: But do you think you can buy it?

JL: I think Lloyds of London will sell it to you. They will do it on an empirical risk basis.

RG: You can do it more easily I suppose in the kidney situation than you can in a lot of other areas. [792] All I am saying is I doubt that if a

kidney donor were to die that his family [795] would have evidence at any place that the risks had really been adequately explained. I don't know what would happen. You guys know better than I.

GG: You are in trouble.

RG: What?

GG: You're in trouble.

RG: Well, all I am saying is that this is something that is on the horizon that is certainly going to happen one of these days.

MF: There is also another problem which may arise. It is if you do fully explain it and you do get a totally informed consent, there is some reason to think that you may not fully exculpate yourself. When you surmount the problem of fully informed consent, I don't think you'll surmount the liability problem.

RG: OK. And one of these days we are going to run into it. Because I can just guess that some normal healthy guy--a red-blooded American boy--gets knocked off as a result of giving a kidney and somebody is going to say, I didn't really understand this or I didn't really think this was going to happen.

HP: I'd think you'll find some court saying that in view of the fact that you have such excellent experience on this, that something must have gone wrong. Somebody must have been careless.

MF: Consent doesn't exculpate them from carelessness so you don't get to that problem. You get to the problem of the validity of the consent. You are suggesting that this is an interpretation of contract problem rather than a tort liability problem.

JL: [805] I think you have a moral responsibility to buy that insurance and to create the circumstances in which it can be bought for people to whom we

subject these risks. Why should they subsidize the cost of insurance, which is what in fact is happening by volunteering that risk. If you can't convince Lloyds of London that there's an actuarial<sup>31</sup> basis on which they can compute the premiums, then you are not able to convey the idea of the risk to anybody. [805]

RG: Well, the problem there is that of the number being done and the risk is very small. I am sure the actuarial figures can come up. But lets assume that the risk is the lowest mortality risk I would guesstimate is the anesthetic risk per se would probably be somewhere in the order of one in a thousand--maybe less than that.

JL: Then you pay \$1,000 per operation premium [808-and] buy a million dollars worth of insurance.

RG: Well, I was going to say you would have a tremendous premium on this.

JL: But that assertion says that you know that the individual is subsidizing the cost of that insurance. You have explained the risks to him but why should you ask him to pay for that insurance?

RG: Well, OK, let me ask the lawyers something. Suppose you get this insurance policy, do you then change any of the legal implications of this?

GG: No.

JL: No, you just pay it when it happens.

BM: Let's be sure we keep distinguished [812] two situations. No. 1--There is something called a "consent" and then the man dies on the operating table, despite the fact that the procedures were carried on in a superlatively careful way and everyone will agree to that. Here the challenge will come up in terms of the litigation that the consent was not really informed, he didn't know that there was really such a risk at all. The consent will be held to be invalid. In a sense you are being held liable

for a assault--or something like that. That is the only way one can think about it. That is the way the courts would deal with it . . .[815] The second one is quite different. The next one says, ok you did a marvelous job at telling him all about these risks. The consent itself is perfectly valid but we are not just going to let him consent to somebody leaving a sponge inside or the fact that you have filthy dirty operating room or whatever. And here the allegation--the way it would be articulated has nothing to do with the invalidity of the consent or information -- would be that there were some kinds of deficiencies or negligent performance on your part which consent or no, you are not going to be able to get away with. Those two are really quite different situations.

RG: Now lets take the cardiac arrest. Now, the cardiac arrest is not attributable to negligence.

JL: And you have told him that anybody who takes anesthetic may get cardiac arrest.

BM: You are probably going to get out.

RG: Well, I can understand it if you leave the sponge in or somebody spits in the wound. But take the thing that is more likely--cardiac arrest or thrombophlebitis. [822]. Any time you lie in bed you might get thrombophlebitis. [823]

BM: We are arguing that that one you can probably get around it if you have adequately have made prior explanation.

MF: It is more than that. I think if you note statistics--you are probably under some obligation to convey some sense of the enormity of the risk, that is that your anesthetic problem turned out to be 1 in 7.

JL: Well, I submit that the guy who voluntarily signs a consent under those circumstances is subsidizing you to the extent of the cost of that insurance.

BM: Subsidizing somebody--you or the donee.

JL: Somebody gets the benefit of the fact who would otherwise have been expected to furnish that insurance.

BM: The surgeon or the donor?

JL: No, I want to respond to that. I think it would negate the fuss and furor that would come about if there were an accident if he were told that you have taken measures to insure him for a half million dollars or a million dollars, that is also a very good way of conveying the nature of the risk.

BM: What kind of insurance are you talking about? You are not talking about liability insurance of any kind. You are talking about a life insurance.

JL: Straight life insurance if an accident occurs during the course of these procedures. This is the risk that he is taking, after all. The question of liability is something the surgeon will have to negotiate with an insurance company as to what protection they will want from you with respect to the standards of your performance. Well and good because there you are then dealing with sophisticated people who have the benefit of all kinds of counsel & experience.

BM: Well, the thing that that would produce would be that Lloyds of London will turn around and offer to pay Bob Chase \$75,000 dollars a year to come and work for them.

JL: Well, that may be a good idea.

DH: Once you open up the insurance prospect--and I agree it has to be opened up--you can't stop it at life. You've got to consider disability. You have a cardiac arrest and you start him up again, and meanwhile he is conked out up here in the head.

RG: Well, this is one problem that might well be focused upon for the simple reason that I don't believe that any of the people doing transplants, at

least at the centers where I have worked, have done a thing about it. I think they go around with their fingers crossed recognizing that this spector is there but that hopefully it's not going to happen to them. Let me ask you a different question. If you go to the dentist to have a tooth extracted or to have a filling and he says I'm going to put a little xylocaine in there. Now in general, if he has any sense at all, he will ask if you've ever had any kind of reaction to this. You may answer no. In the first place nobody hears when they ask you-- maybe there is a nurse there but maybe there isn't. And in the second place, they don't record it. Even if you haven't ever had it, it is conceivable that you could end up something or other and can go into shock and die. Now, under those circumstances what is the legal situation there? Suppose this happens to somebody and his family sues the dentist?

MF: With respect to the dentist, there is inquiry as to whether the standards of care that prevail in the community as to asking those questions. If he has met those tests, there is no liability.

RG: The testing business should be done but I have never seen a dentist who has done it. Maybe he says I did it or maybe he says I asked the patient, and the patient told me 'no'.

MF: Well then he has proof problems obviously, if he says he has done those things. There are points at which the standard we've been talking about just doesn't apply. There are times in which, no matter what the prevailing medical practice is in the community, the courts will say that is just a silly practice. And this is an important addition to the formulation that Josh has been setting forth during these sessions. There is a point at which the courts will say this is just so screamingly careless, we don't care if every physician in the world does it, it is wrong--

it is negligent. So there is always that limitation. It is a matter of lawyers educating judges about medical practices. There is loss and some slippage all along the way. Your specific situation doesn't strike me as the one where the courts would be likely to say that pretesting is essential. They might want to know how many people are allergic to novocain, xylocaine or something like that and so forth. But at some point the courts are just going to throw up their hands and say "that is enough."

BM: I think Marc's point is very well taken. And it is critically important one. I do think though it is worth adding and he knows much more about it than I do, but to keep it in context, that the likelihood of a court's doing that is statistically very low. The courts do it and are not always guided by the community professional standards. But it is really quite infrequent.

MF: It is growing. There are some states that don't even require the plaintiff to show that the prevailing medical practices [854-so that] you can read a textbook to the jury. You don't have to have a doctor, you just have to have a textbook. You don't have to show that the textbook conforms to the local practice. You just read a textbook to the jury and the case is made. And the courts, rightly or wrongly, are starting to think they know more about medical practice in some areas than they do. The first explosion came in the sponge cases when doctors came in and said well, the practice clinically was thus and so, and the courts would say, well, don't tell us this. There is a sponge in there and that just must be wrong; somebody must have made a mistake and we are not going to play games about it. And the case of X-rays. The court's say don't tell us that about X-rays; everybody knows that X-rays should be taken. We don't

care what the practice is in the area. Courts are just beginning to move in this area, and there is some suggestion that this is breaking across the standards of medical practice. Physicians are just going to have to take X-rays. [858] I don't mean to overstate this. I am just suggesting the trend is certainly to open this up.

BM: Unless you think you are really entirely alone in this regard, let me suggest that it has happened to other people too. The accounting profession has gone through a very considerable revolution over the last ten or fifteen years. And as a result of what were perfectly clearly acceptable standards of accounting procedures, people wound up being mulked out of hundreds of million of dollars and the courts just said, "I don't care what the public accounting procedures are or what public accountants do, they just better do better than that before they go around making certifications. You better jack up your generally acceptable accounting principles or run the risk on whatever losses flow from it." Actually, in the particular case, this was all to the good. [864]

MF: Let's go back to Josh Lederberg's subsequent point. Part of what the donee is paying for in this operation really involves extenuating risks to other people. He is paying for physicians, paying for beds, and paying for operating rooms. He is also paying for possible risks to the donor or it could be thought of in that situation as spending for what he is getting from this operation.

RG: But now you get into the class business again. Of course, many of these transplants so far have been done in a clinic and nobody is paying for them at all. But suppose you say, ok, a guy ought to pay for an insurance policy and let's say it is going to cost a thousand dollars. Then you put an added burden on the guy who really can't afford to do this anyway.



- JL: Well, the donor can waive it, he ought to have the option of waiving it. It ought to be laid out very clearly to him that he is subsidizing that part of the cost of the care of the patient. It regularizes the nature of the process of consent.
- HP: But it also may create an additional consent problem for you if he dies.
- RG: I'll bet you get this out into a public arena, the guys who are doing transplants are going really tear their hair out because as much as they are aware of the problem. . .
- JL: [872] What kind of hari-kari is it going to be when the guy dies? The problem is really going to catch up with you and it is going to be that million bucks all at once instead of a thousand dollars at a time.
- DH: A brief comment on the standard practice [874]. I think perhaps there is some complexity here on two levels. One, is that the standard of practice in the relevant community in most instances will not be geographical; it will be some kind of national community of those university hospitals that are in the frontier in the field. The next thing is that in some cases there will not be any relevant community at all. [875]
- BM: Or it may be the first time that this particular variant in the operating room has been tried.
- RG: [876] That's exactly right. I was wondering about that particular point as Josh was asking about it, whether you could really buy insurance. I am not at all sure that you can allow yourself to be or should be locked into that limited situation in which by some magical way there has already been built up an actuarial basis of practice. When you are on a frontier of operation, you just can't play this game.
- JL: Then the research and teaching hospitals association self insure and spread the risk in that fashion. The point is there is a risk there.

There is that million dollar liability that has to be on somebody's shoulders. Do you want to leave it to the vagaries of probability and put it all on one guy under unpredictable circumstances where things may go very, very badly for the whole profession because of that or do you want to spread it around among every case?

BM: The answer to that question is a very complicated one. Marc is working with it in other areas. I don't think there is going to be any automatic answer to it. It seems to me if one comes down with the view that the advancement of the research and the advancement of the experiment is the more critical need that you might very well conclude that as long as you lay it all out, as long as it is all elaborately explained to the donor, as long as you say, look, the one thing we will guarantee is that we are liable as long as we leave the sponges in--let's get that case out--but we are telling you that this is an experimental situation in the sense that it has not been tried before, that it is a new and novel, surgical technique that is being tried here, and of course there is some risk involved in that, it doesn't seem to me in the nature of things inevitable that you can either take the option of (1) not going ahead with it or (2) going ahead with it and taking the risk and the guy says, ok, I will take those risks. The alternative, that is, the attempt to insure in all cases against whatever is a novel development is going to be a very expensive one which is going to have some repercussions obviously on the professions and the hospitals trying to deal with novel operations.

JL: I would argue that the proper information on this point would include telling the donor that he is giving you something which is worth X dollars which would have been the cost of an insurance policy if there were one.

BM: No, but it has an infinite number of dollar signs or dollar numbers after it. No such insurance can be bought.

- JL: Well, I think one way of stating it is, were something to happen to you there would be possible damages in the range of half million or a million dollars and that if we told you that the risk is in the order of one part per thousand that means that it's worth to you about a thousand bucks.
- MF: Apart from this, would it be consistent to tell the man, look, this kidney is saving this man from going on a kidney machine at \$8,000 a year for the rest of his life. Recognizing that you are subsidizing this man twenty more years at \$160,000, apart from what we are talking about today, would you want that in the consents?
- JL: Well, no, because the value to the donor is not the value to the donee in this case. There are different measures. The donor has his own kidney. He doesn't need the machine; he doesn't need the \$160,000.
- MF: But he is subsidizing the donee to that extent, assuming the donee has the alternative of going on a kidney machine.
- JL: Except there are other donors who might set a lower market value on their kidneys.
- MF: Isn't that equally true today--there are other donors who might be willing to do this without the insurance policy?
- JL: It is the value of what they are giving; it is the risk times the expectation of damages.
- BM: But, Josh, all I'm really saying is we can not automatically reach the social allocation position. Given enough instances, I am completely with you but, if you want to use a crude analogy--if you are messing around with the astronauts, let us say. Clearly this is a highly novel and dangerous operation you are about to go into and [898] it isn't a matter of who's negligent. . . .

- JL: But those guys are insured. That is just exactly the point of this. Their families aren't going to have to worry if in fact something happens to them.
- RG: Are they in fact?
- JL: In fact they are, they have got the royalties from Life magazine, that is, the families of the astronauts have the royalties.
- MF: The original nine, but has that been extended on?
- RG: There is a hugh number now. Those royalties wouldn't go to cover all who are involved now.
- JL: Well, they are not all exposed to the same degree of risk.
- HP: Well, the government might insure. If necessary, Congress will pass an act for the benefit of the survivors.
- JL: I think people in the military are much more to the point.
- BM: Donors are none of them under orders to do this.
- JL: I am not talking about the astronauts, I am talking about military service in general. [903 . . .]
- MF: What would you people do today if, as a result of a radio appeal in Fresno, seventy people came forward with perfectly usable kidneys, all the psychological problems were resolved and you had 20 or 30 patients around all of whom needed transplants and none of them with any money.
- RR: What would we do?
- MF: Yes. In other words, you've matched up twenty pairs of people who need the organs. What is the relationship between you paying donees and your impecunious donees?
- RG: The problem is, as you know, we don't have any endowment for the hospital, we don't have any source of funds excepting patient revenues. We do have a clinical research center which is funded by NIH. Most of the patients

we work with are in the clinical research center so funds are not a problem except that the numbers are. There are only a limited number of beds available. We are in the process now, as a matter of fact, of putting together an application for a transplantation center. But the answer to your question is of course we couldn't for lots of reasons. The problem of managing these people post-operatively is still a very substantial one. We sort of gloss over it, but the business of maintaining the transplanted kidney so that it is not rejected involves a tremendous amount of time, effort and people, and even if money wasn't the object, we don't have the personnel nor could we get them. This isn't something we could just train people to do in a few seconds. [931] It is a very complicated business. So that until the control of the rejection phenomena really gets worked out to a greater degree, the numbers game isn't going to be terribly important from a practical point of view. The facts are that now we can control the rejection phenomena to a pretty impressive extent, but that is only because there is very careful juggling, monitoring and so forth. On the other hand, it seems to me very likely that five years from now things may be different. Just as when penicillin first came along, the business of evaluating it, knowing how much to use and how to use it, took a lot of skill and study. Now for many purposes you don't have to be much of a genius to use penicillin; the thing is pretty well worked out. And now this may well be true in the transplant area. For the numbers you mention, we couldn't handle them: no place that is doing transplants could handle them. What I think they would do is line them up and say, we will get you in as fast as we possibly can.

DH: I would like to raise with you a question. It may not be too serious but it relates to another aspect of consent. We have been exploring

what constitutes informed consent. [938] Now, we haven't said very much about what constitutes freely given consent and I worry a little about that. For instance, Bay mentioned before the strong feeling in the family both negative as well as positive and I can easily envision all kinds of family pressures that would lead somebody to give an organ which he would terribly regret later on. [941] The other side of that coin is that he regrets not having given it because he was so terribly attached to somebody and so on. But I can pretty well imagine the situation where he damn well didn't want to do it--maybe he wasn't all that quite clearly formulated in his mind, but there were subtle and nevertheless powerful family pressures. Well, that is one problem. The other is there are medical pressures.

BM: I can see Grandma saying " I will cut you off in my will if you don't do it."

DH: A clear case of medical pressures would be where there has been some lifelong dependence on the physician and this same physician is urgently looking for someone to give an organ. I can almost imagine, probably stretching things, even in the case of a new physician that the process of providing adequate information might lead to a subtle kind of duress. This may be clearly drawing it out in a rather fine way but suppose the physician spent twenty or thirty hours with a patient informing him really thoroughly about what's involved. Now obviously because he cares tremendously about this and builds up a rapport with the patient, in any case, family pressures, medical pressures, is there any problem about what constitutes freely given consent?

HP: Sure. I wonder if we don't need to develop something like a medical counsel to the situation, somebody who is not directly involved.

DH: An Ombudsman.

HP: Well, sort of, yes. For example, is it routine to have psychiatric counsel of the donor if it is a research hospital?

H: Perhaps it ought to be.

DH: The tendency has been, both in Europe and this country, to have some psychiatric screening. The main thrust of it is to screen out the guy who is teetering on the brink of a psychosis and doing this thing might throw him over. I don't know how much really there has been in the way of continuing relationships. In the case of this one project at Stanford, there is and I think it exceeds any project I am familiar with where the psychiatrist is following up these people as long as he can keep in touch with them. But I think that is rare.

BM: [953] You would want to include variables here, that is, something about the intellectual capacity of the donor as a sort of a check. One of the risks involved is making some formal requirement or prescription which would make the information given out by the doctors completely meaningless. Thus is not quite a duress case.

GG: In terms of voluntary consent at a research hospital dealing with the donors, dealing with an experimental subject, you are clearly in a vulnerable position when the consent is challenged. [957] Outsider would be suspicious that you were interested in other than his immediate health.

BM: You just have to see how concerned Hal Holman is about it. He is very worried about it. And I have reference to his constant concern with the conflict of interest. [958]

GG: And with good reason, I suppose, in terms of any kind of challenge. And you push more and more towards the medical Ombudsmen idea, and you get further and further away from the real people involved, that is, not

simply the guy next door, in another department, but someone completely outside whose concern is beyond the particular hospital involved.

MF: I think there would be advantages from your standpoint if you distinguished between having the surgeons or an intern explain dangers to a particular patient from having the patients own physician explaining the situation to him. The psychological effect may be different.

DH: That would be very interesting. A few years ago the same patient on the same day was approached by two doctors and the order of approach was randomized and he didn't know either one of them, but the doctors were about the same age and as similar as possible, and one said I am Doctor so and so, internist, I am Doctor so and so, a surgeon and each said, tell me your problems. And they got two different stories. [965]

GG: What internal procedures do you have outside the transplant area in terms of the review board sort of thing which is used in human experiments? At least there you get a number of departments represented and you eliminate many or any direct involvement. The same people involved in the experiment are not involved in judgment. On the other hand, it is part of one hospital or one medical center and to that extent you could say they aren't fully independent.

RG: 969] All experiments using any human subjects get some review and build in some kind of review. But the reviewers are part of the research establishment. On the other hand, it is difficult. When we first started this, I started out appointing a committee of people who were not involved at all and then there was a lot of criticism because they weren't in a position to understand what goes on.

GG: And the people you are appointing are presumably medical men. If they don't understand it how can you expect the patient or the public to understand?



RG: Well, the trouble is that you never really can do this. You see, of course, there are varying kinds of situations. Let's take the patient who is suffering from maglinancy, and he is past treatment in any acceptable form of therapy, and you are going to try a new drug on him. The drug is admittedly a dangerous drug. It is a two-edged sword. In my view, given a [976] reasonable explanation and given that you have got a patient who is doomed anyway, he has got a lot to gain from this. If the drug happens to be effective it may mean all the difference in the world. But the place where you really get into trouble is, when you do things to people who aren't in a life threatening situation. I mean, the research may be important to try, but there is a certain risk to the patient. It is more closely allied to the business of the kidney donor. He is involved in something that stands to get him very little except at most the psychological benefit. And he takes a risk. But the problem of testing new drugs--there is a lot of criticism and appropriately so, of the use of new drugs--there are huge numbers coming out. A lot of them are used without any sense of reason. There are very few drugs, if any, that aren't potentially dangerous. Some are potentially dangerous on a very tiny scale: some are potentially dangerous on a very large scale. How do you evaluate these drugs? How do you get information on them? How do you do it and at the same time protect the patients?

DH: One further response to the question about current practices--a number of these transplantation centers have at least tried to maintain the independence of the physicians responsible for termination from the physicians responsible for transplant. I gather there is a certain amount of practical difficulties, but at least the effort has been made.

- MF: It just dawned on me that the licensed practioners on a review board which we talked about yesterday should be supplemented by some others who are totally outside the hospital, indeed if not outside the city,
- GG: [986] Outside the department and outside the hospital. . .
- MF: At least outside the department, outside the hospital, outside the city, because the local medical groups might be subject to certain pressures.
- RG: That is not what I was thinking. I see your point, but, again, it is the practicalities. Where are you going to get them?
- GG: The very fact that you are reluctant and that you have difficulty dealing with the experimental drug situation with the fellow who isn't part of your research establishment, obviously you would have more difficulty with a physician who is not in the experimentation drug or transplantation business. But I guess part of this would involve taking on a lot of added bother to educate the autonomous judge.
- RG: I'm not sure that you could set up this business we discussed yesterday, a multi-disciplinary group. Maybe a couple of you guys ought to be sitting on it.
- BM: I don't really understand Marc's last point. I understand its motivation, but my mind, at least, has certainly not been going in that direction. If you put it back into the transplant situation in which something like section 3 is operating, for example, to the very extent that you are thinking about somebody who is just about to die, you are in a rapidly moving situation: you are practically going to have to grab the next three doctors coming down the road. Either that or give up on this possibility.
- MF: I am not sure you cannot have a panel, a Bay Area panel, or a San Francisco panel. I am just very troubled about this. I think changing it

from M licensed practioners to N licensed practioners doesn't seem to do anything unless there are very careful protections built in. Now maybe the patient's own physician would do. But then I do have other problems. Maybe you want people from other disciplines. I'm not talking about going five or six hours away. I'm talking about someone up in the city. I wouldn't want anyone from the Palo Alto clinic or the Stanford Hospital doing this kind of thing or at least controlling the board. Maybe one local member of the board could explain what it's all about.

GG: [1998] The conflict of interest point, apart from individual problems needs a day by day procedure. But there is obvious relevance of setting up some review for public consumption and possible court challenge. It is the one thing which, as you all know, the courts and the public generally can grab and are likely to get their hooks into more easily than evaluating esoteric medical evidence. You have faith in the judgment made by the people sufficiently disinterested and when sufficient institutional safeguards with the interests of the patient in mind exist, some kind of outside representation is awfully important.

HP: I like the multi-disciplinary approach, myself. Among other reasons, questions typically are not going to be, I suppose, the refined, esoteric questions. They are going to be questions of judgment.

RG: We face this problem now, not to the same degree. I was referring yesterday to one of the guys who was doing cardiac surgery and who was obviously operating on a lot of people who didn't need surgery at that point in time. There's no question they had a heart disease and they might have eventually needed it, but he would take these people because there were a lot of them around and it gave him relatively good risks.

Take a patient with rheumatic heart disease. They are classified sort of Roman numeral I through IV and the guy who is IV is really in ghastly shape. He is really a bad risk just to walk across the room. On the other hand, if we do one of these procedures on him, you know that if it is successful, then you have real reason to say: this really does offer something. Now what this other guy did was to start with grade I and went through a very big series but not a very satisfactory one. Now, this isn't quite as dramatic as the other thing we were talking about, but everybody in medicine who knows anything about the field knows this guy was pulling this and he doesn't enjoy a very great reputation now and he never did. A lot of people, professors of surgery in medical schools are unhappy about it, but he has made a lot of money out of it all. All I am saying is that this kind of thing goes on all the time and it never really surfaces. [013] We are very reluctant in our profession just as you are in yours about blowing the whistle on a charlatan. Nobody does it. It's been my experience in any city you want that you will find both lawyers and doctors who spend all their time trying 014-ambulance type cases. We all know what they are going to say, they've said the same thing for years every day and nobody does a thing about it. In this transplant area we've got something so dramatic that I don't think you are going to get away with it very easily. But it is an extension of what is really going on in other areas right now.

DH: One thing has been done to protect someone from coercive family pressures. When the prospective donor comes forward and says he's ready or almost ready, he is told that (a) that he shall have some time to reflect on it if his first pass is not sufficient and (b) that if he should decide on reconsideration that he doesn't want to do it that the doctor will say, falsely, that for medicalological reasons he shouldn't, not that he has to

take responsibility for it, but that he couldn't be accepted. [020]

This sort of thing is covered in a volume called "Ethics and Medical Progress."

BM: Our time is sliding away from us. First of all, I'd like to ask a general question: Is there anyone who has some other major problem topic which he specifically thinks should be mentioned which has not come up so far? [025]

LB: I think there is just one question that occurred to me that one would have to link up. This is something which was skirted carefully by the medical people. It is the link up between termination and of euthanasia. I think that would have to be mentioned at least because if you don't mention it, somebody is bound to raise it. The general question of course would be: for the purposes of social utility, how far you wanted to go up the life scale in order to terminate? For instance, here you have the question of the person who is discerebrate, and he is a vegetable. There are different kinds of vegetables. How are you going to limit the termination to only those people who are discerebrate? Isn't this opening up a whole range of possibilities for terminating life on the grounds of social utility? It seems to me that quite rightly--this question was skirted, but in any case I think the statute has been left open on the kind of question.

BM: Well, certainly the question is enormous. I don't think I understand how you get there from either the very conservative statute which we were talking about yesterday or even with the inclusion of what was section 4 which in a sense involved the discerebrate, but also had built into it this other judgment that if a man is going to die within 24 hours. I am not fighting the existence of the problem, but I am not quite sure I see how you have gotten to it.

LB: [035] Well, first of all, I think you have this question of the person who is not really dead yet, but is going to die within twenty-four hours. You already defined what discerebrate is in a very limited way, but still, this is contrary to the type of notion that people have of a person being actually dead. You are opening very slightly an issue you could open up further. Obviously it is new in the very fact that you make a distinction between the person who gives his permission to take his organs out after he is dead and the person who consents to have his removed when he is discerebrate. Sections 1 and 2 are on the very, very lowest end of the spectrum and discerebrate is one step up on the spectrum and another step up would be the question of euthanasia. Do I make myself clear?

BM: Yes, I understand.

LB: There are two cases. One are the extreme cases such as 1 and 2 and then you are going up on the scale to the discerebrate, and you take the next step up, and the next step, and then you get into the big question of euthanasia which is really on the upper end of the spectrum.

BM: Is there anyone else who has some item block they would like to discuss or some blockbuster. I have in mind first, my own desire and at least Dave's expressed desire to at least raise this question in the few moments that we have left. What have we to say further that we have not yet said by way of suggestions, comments, and so forth, to the Russell Sage people on the conduct of their general study?

DH: Well, I have one. It seems to me that they might very well foster, stimulate, even conduct, some research on public attitudes toward the type of questions which we have been discussing. Now it is an odd fact actually that any issues surrounding death are very poorly investigated. If you don't believe me, go to textbooks of psychology and sociology and see if

you can find death in any index. Most of the textbooks of psychology that are widely read do not have death in the index--at least the last time I looked, which was three or four years ago. Psychiatry is just about as bad, almost as bad, in spite of the fact that we have clinical responsibility for dealing with problems of this kind. Freud, of course the most influential person in this field, was mainly preoccupied with how fear of death wasn't really fear of death but fear of castration or mutilation or something else, but not the real thing. And not very much has been done to correct that until fairly recently. So I think it is a generally neglected research area in the behavioral sciences, including psychiatry. But now the transplantation thing might introduce a very important element. I would not be surprised if some of our guesses about traditional attitudes which we have been making the last few days--and I have been as much at fault as anybody--may be very weak guesses. I don't know what the effect on the public at large of the imminent prospect of transplantation is, whether it might modify some traditional attitudes. I can envision that Russell Sage might sponsor some survey research on attitudes in this area. I would want to include in that samples of those groups who are known to have very strong feelings in this area deliberately because they would be missed if you had a neat national sample stratified by class. You probably wouldn't get any Seventh Day Adventists or orthodox Jews. So I have been surprised in looking through this volume (?) that although there are several quotes from Pope Pius the XII which astonish me in light of my stereotype of what the Catholic position would be on termination and other things like that. It is way off. Of course, I'm assuming that Pope Pius represents the Catholic point of view. In any case, at least it surprises me. This is one recommendation I would like to make.

BM: There was a recent interesting cross anthropological, cross cultural study on attitudes toward death of which I just happen to have a copy. It's a monograph. It was produced at Berkeley by someone who is no longer at Berkeley now although he was there when he did it. But I do have a copy of it at home, and I know that Brim knows about it because that's where I got it.

LB: There is also a book by a fellow named Emanuel Jacobovitz who is now the chief Rabbi in England and it is entitled "Jewish Medical Ethics". I tried to get a copy at Stanford and also the Lane Medical Library, and there is no copy. I think it's a 1967 book. So I think that would be a comparable thing to look at and he of course, represents the orthodox viewpoint and is very highly articulate. He would be a person who would discuss all these questions, I imagine, although I have not seen it.

DH: [072] I'm suggesting specifically developing material on transplantation.

BM: That is a very interesting thought.

MN: What about the studies about drugs that affect the mind and have an effect on the nervous system? I would be fascinated by studies in this area and studies of the ethical, political and social problems involved. I understand we are just about there and the impact on politics and society has hardly been scratched.

BM: I'm not fully sure I understand your point. As I understand the study itself and, Bob, you know much more about this than I, the study itself is specifically focussed on termination problems, the doctor in the hospital in the role of what has been called the supervisor of death.

DH: Michael's point is well taken. You're quite right, Bay. But at least there was a broader interest when Bert Brim spoke to me about this a year or two ago. . . It was a very broad interest in the impact of bio-medical advances upon society. And in other areas Russell Sage is actively



sponsoring the training of social scientists in biological techniques for basic research. For example, the physiological effects produced in a small group. When we interact with each other, there are integren [079] changes which take place. Are there some rules which guide those changes and can we find them? Now, in this area which Michael brings up, I don't think we are nearly as far along in the scientific end of it as we are in transplantation. In another sense we are up to our eyeballs in social involvement, so we are much further advanced there. More broadly speaking, chemical influences upon behavior, the area of possible hormonal influences upon brain development. It might be realistic on a time scale of a decade or two. Consider the social problems if you understood enough that you could substantially modify the development of intelligence or the development of aggressiveness through hormonal influence at the right time in development. I have science fictioned this in teaching; but supposing we solve the problem, what social questions would arise? I suppose you would need international agreements before you could effectively apply any of these things? I would try to make the case that you would. It would be very difficult to do on a national basis. Well, it has a more science fiction character because there is no assurance that this will not come to pass. To give you an example of the state of the art, most of the work which is evocative of what might come to pass is still with rats or mice and so on. There is only one important line of work with monkeys to my knowledge. So it's some distance down the road. Another area where there is some wide open undisciplined prospecting going on in drugs that affect the brain in the generally magical hope that some of them will do wonderful things for us, free us, advance us and so on. My own judgment is that a lot of it is already and will increasingly end in disaster. That isn't mainly medical. [090] That's

another problem of drug use and abuse.

MN: I was thinking also of the electronic stimulation. I have seen that famous movie "Del Godimus" and I would include that.

DH: Sure. That's going to be a very active area of investigation undoubtedly in the next ten or twenty years. We may be saved a little bit by the reductionistic philosophy which guides most biologists at the present time. They do not want to mess around with whole organisms or complex circuits so they are going kind of slowly but if there were any sense of shift into that area, we might have a large problem on our hands in a very short time, in being able to modify socially significant behavior through remote stimulation. Del Godimus has now got a couple of people working with chimps in New Mexico in an Air Force set up where they are trying to perfect the technique of remote stimulation of the cortex (094). You don't really have to be with the animal, you can be some considerable distance. People from Seattle are doing this in Africa in the natural setting. You sit off a mile or two away and push the button and the animal suddenly attacks another animal--something like that. I don't have any feeling for the potential applications upon human subjects.

MN: It was much further advanced in the movie that I dreamt it was.

BM: I hope you didn't mean to suggest by your last sentence that the art is so advanced that people in Seattle are in fact working in Africa.

DH: Oh, no, no. They do at least have to go to Nairobi.

MN: I know there are some people who insist that there are people in Moscow doing that to us.

RG: I'm all in favor of it. We will put those devices in the heads of the faculty and I'll sit down in the Dean's Office and push the buttons.

HP: Actually we'll have them over there in the Provost's Office and controlling the Deans from there.

BM: We are, I guess, at the end of our discussions. I am very, very grateful to all of you for your participation.